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CHAPLAIN AS RESEARCHER: GROWING THE EVIDENCE BASE FOR SPIRITUAL CARE IN PALLIATIVE CARE

Supportive Care Coalition
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Objectives

- Articulate at least three benefits of evidence based spiritual care to chaplaincy practice and recipients of care
- Demonstrate familiarity with key examples of evidence based chaplaincy/research
- Understand venues and opportunities for individual professional development and involvement with research



Outline

- Spiritual roots of evidence and research
- Benefits to spiritual care profession, practice and recipients of care
- Palliative spiritual care evidence
- Chaplain researcher types – opportunities for all chaplains

Sacred Research

Rabban Gamliel the son of Rabbi Judah HaNassi said: It is good to combine Torah study with a worldly occupation, for the effort involved in both makes one forget *avon* (sin). Torah study without occupation, for the effort involved in both makes one forget *avon* (sin). Torah study without an occupation will in the end fail and lead to *avon* (sin).

Pirkei Avot 2:2, The Koren Siddur

Hillel said... Do not say anything that cannot be understood [at once] in the hope that it will eventually be understood. And do not say I will study when I have the time, for you may never have the time.

Pirkei Avot 2:4

Pirkei Avot = A compilation of ethical teachings and sayings from Rabbinic Judaism

How do you understand your sacred obligation to chaplaincy research?

- Texts, teachings, rituals, liturgy other practices that support an interest in learning about or contributing to the literature of empirical chaplaincy evidence
- Community connections
- Care of self – diversification of work encouraged resilience and prevents burnout (and we can take all we can get in the challenging system we are working within)
- Meaning
 - Clinical work: challenging, gratifying, and fascinating

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Sacredness of research

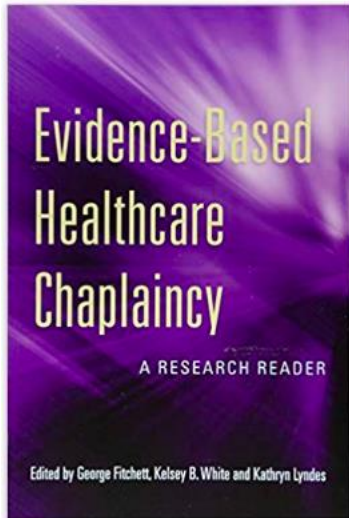
However...

- Research: Means of connecting
 - With mentors
 - With colleagues (from all over the world!)
 - With mentees
- A way to remain a perpetual student
- Ultimately, research is a way of seeking meaning from one's profession or one of many ways of seeking meaning from one's work

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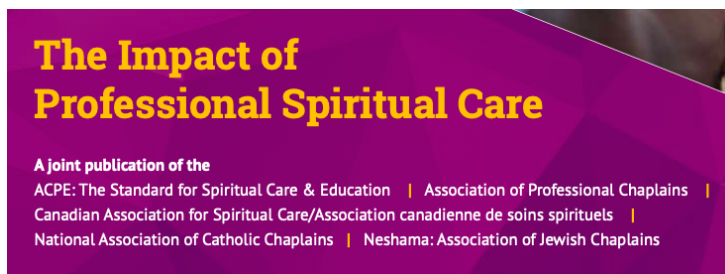
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Evidence Based Spiritual Care



The first reason is that we need research to help us know if the care we are providing is having the effects we hope it will have. As Canadian chaplaincy researchers Thomas O'Connor and Elizabeth Meakes wrote in 1998 in the first paper to use the term "evidence-based pastoral care," "Evidence from research needs to inform our pastoral care. To remove the evidence from pastoral care can create a ministry that is ineffective or possibly even harmful" (p.367).

A Work of Evidence Based Spiritual Care Art....



Spiritual Needs and Chaplain Care in Palliative and End-of-Life Care

Palliative care has been developing an important body of research about patient and family religious/spiritual concerns and the spiritual care provided to them.

Several chaplains have been among those creating comprehensive overviews of the existing research about spiritual care in palliative care.^{50,51}

What does chaplaincy look like in palliative care?

The importance of attending to religious and spiritual concerns in palliative care is widely recognized in practice guidelines^{52,53} and in national and international consensus statements.^{54,55} Chaplains are recognized as the spiritual care experts on the palliative care team.⁵⁴

- A 2016 study of 410 U.S. palliative care programs found that only 38% had funded chaplain positions.⁵⁶
- A 2017 study of 382 chaplains working in palliative care⁵⁷ found that chaplains had high levels of
 - integration on the interdisciplinary team
 - involvement in addressing treatment decision making and existential and spiritual distress.

Are palliative care patients' spiritual needs being addressed?

- A 2007 study of 230 cancer patients found that
 - 88% reported that religion or spirituality plays an important role in coping with their illness

- 72% reported their spiritual needs were met minimally or not at all by their medical team
- 47% reported their spiritual needs were met minimally or not at all by their faith community.⁵⁸
- Several other studies examined levels of spiritual pain or spiritual concern in patients receiving palliative care, showing notable levels of spiritual distress and unmet spiritual needs among these patients:
 - 61% of 57 hospice inpatients reported some spiritual pain in a 2006 study in New York.¹³
 - 44% of 91 palliative-care outpatients reported some spiritual pain in a 2011 study in Texas.¹⁶
 - 86% of 69 palliative-care radiation outpatients endorsed at least one spiritual concern in 2011 study in Boston. The median number of spiritual concerns in the sample was four.⁵⁹
 - In a 2011 study of 113 patients in an inpatient palliative care unit examining seven dimensions of spiritual need (such as hope versus despair, wholeness versus brokenness, and guilt versus forgiveness):
 - 42% of the patients had no spiritual distress
 - 44% of the patients had distress in two or more dimensions
 - 23% of the patients had distress in three or more of the dimensions.⁶⁰

How do chaplains benefit palliative care patients and programs?

- Several studies have shown benefits associated with spiritual care:
 - In a 2012 analysis of 3,585 U.S. hospitals, the hospitals with chaplaincy services had higher levels of enrollment in hospice care and deaths occurring at home instead of the hospital.⁶¹ (Other studies have demonstrated that patients prefer to die at home.)
 - In a 2007 study of 230 patients with cancer:
 - Patients who received spiritual care from the healthcare team, including chaplains, experienced a higher quality of life at the end of life than patients who did not receive spiritual care, were more likely to receive comfort-focused care (such as hospice), and were less likely to receive futile aggressive care (such as intensive care unit [ICU] admission or ventilation) in the final week of life.⁶²
 - Patients who reported their spiritual needs were inadequately supported by the healthcare team were less likely to receive comfort-focused care in the final week of life and had a higher cost of care in the final week of life (\$2,100 higher, on average, than those who reported their spiritual needs were met).⁶³

What happens when palliative care patients and their families don't have access to chaplain care?

- In 2008 and 2010 studies of families whose loved ones died in an ICU, it was found that a high proportion of family members experienced serious emotional distress in the subsequent

months, with poor communication about treatment decisions with the healthcare team being described as a factor that may contribute to this distress.

- Up to 20% suffered from depression.
- 14%–35% suffered from PTSD.
- 46% had complicated grief.^{64,65}

Does chaplain care affect how family members view the care a patient received in palliative care?

- A 2007 study of 356 family members whose loved ones had died in one of 10 ICUs in the Seattle area found that
 - 40% rated the chaplain care as excellent
 - 25% rated the chaplain care as very good
 - higher satisfaction with spiritual care was strongly associated with higher satisfaction with ICU care overall.⁶⁶
- A 2014 study of 275 family members whose loved ones died in an ICU at Harborview Medical Center in Seattle collected data from hospital chaplains about the care they provided to patients and families in the ICU.⁶⁷
 - Analysis revealed greater levels of spiritual care were associated with higher ratings of overall satisfaction with ICU care.
 - Greater levels of spiritual care were associated with higher levels of satisfaction with treatment decision making in the ICU.

Significance of/Significant Literature Reviews

Literature Review - Testing the Efficacy of Chaplaincy Care - 2012 -

<https://www.healthcarechaplains.org/templeton-research/tr-literature-review.html>

“focusing the research agenda in the area of **palliative care and end-of-life care** opens the possibility of demonstrating value in an area of care where that value and efficacy are already often assumed and where much current attention is being focused by policy makers and the general public. Furthermore, this area of health care offers several options for possible relevant outcomes where chaplaincy involvement might prove to have positive health benefits. There are at least three possible outcomes for chaplaincy care that could be investigated as contributors to positive health outcomes- improved patient and family satisfaction, amelioration of spiritual struggle, and improved alignment of patients’ goals with treatments.”

Kalish N. Evidence-based spiritual care: a literature review. *Curr Opin Support Palliat Care*. 2012;6(2):242–246. doi:10.1097/SPC.0b013e328353811c

“The majority of patient-focused studies concentrate on oncology and **palliative care** patients...Practitioners continue to view spiritual care as part of their role to a greater extent than they provide it. This is often attributed to the absence of consensus in the field regarding the definition of spirituality, a lack of clarity of disciplinary role, and inadequate education for nurses and doctors about spiritual care.”

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Palliative Care Chaplaincy Evidence Base & Research

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- Glombicki JS, Jeuland J. Exploring the importance of chaplain visits in a palliative care clinic for patients and companions. *J Palliat Med*. 2014;17(2):131–132. doi:10.1089/jpm.2013.0523

Transforming Chaplaincy

TRANSFORMING CHAPLAINCY ABOUT NETWORKS GRANTS

Transforming Chaplaincy grew from a pioneering partnership between Rush University Medical Center, Brandeis University, and the **Joint Research Council**. It continues today as a central resource for fostering research-literate chaplaincy.

We serve a wide variety of diverse communities—including chaplains, educators, and healthcare administrators and professionals—by enhancing their practice with the best research and scholarship now available.

[LEARN MORE](#)

I AM A... CHAPLAIN

- I'm just getting started
- I want to take my research further
- I want to connect with people
- I want to search for resources

- Fitchett G, Pierson ALH, Hoffmeyer C, et al. Development of the PC-7, a Quantifiable Assessment of Spiritual Concerns of Patients Receiving Palliative Care Near the End of Life. *J Palliat Med* 2019.
- Puchalski C, Ferrell B, Virani R, et al. Improving the quality of spiritual care as a dimension of palliative care: the report of the Consensus Conference. *J Palliat Med* 2009; 12:885.
- Jeuland J, Fitchett G, Schulman-Green D, Kapo J. Chaplains Working in Palliative Care: Who They Are and What They Do. *J Palliat Med* 2017; 20:502.

Chaplaincy Innovation Lab

EVIDENCE-BASED Practice | Social Work Policy Institute

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Title	Creator	Date	Item Type
A Response to Geriatric Oncology, Spirituality, and Pall...	Handzo and Bowden	2019	Journal Article
A Survey of Chaplains' Roles in Pediatric Palliative Care...	Cadge et al.	2012	Coordinating Assessme
Becoming a Spiritual Care Generalist: Spirituality Trainin...	Penate et al.	2020-02-01	Spiritual Needs: A Cros
Chaplains Working in a Hospice Palliative Care Team Re...	Hasson	2006	Narrative and Psychom
Coordinating Assessment of Spiritual Needs: A Cross-...	Perry et al.	2020-02-01	Assessment Tools Use
Cultural, Religious, and Spiritual Issues in Palliative Care	Mathew-Geevarughese et al.	2019	Care (STBA)
Development of the PC-7, a quantifiable assessment of ...	Fitchett et al.	2019	Author Perry, Kathleen
How and how much is spirituality discussed in palliative...	Best et al.	2019	Author Parker, Ryan
Improving Palliative Care Chaplain Communication with ...	Steinhauser et al.	2020-02-01	Author King, Heather
Knowledge and Perceptions Regarding Palliative Care A...			Author Steinhauser, Karen
Palliative care: an essential facet of universal health cov...	Knaul et al.	2019	Publication Journal of Pain and Syr
Policy Changes Key To Promoting Sustainability And Gr...	Kamal et al.	2019	Management
Quality of care, spirituality, relationships and finances in...	Abu-Saad Huijjer et al.	2019	Volume 59
Spiritual coping and psychological symptoms as the en...	Gryschek et al.	2019	Issue 2
Spiritual needs and communicating about death in nonr...	Cai et al.	2020-01-23	Pages 577
Spiritual needs and communicating about death in nonr...	Cai et al.	2020-01-23	Date 2020/02/01
Spirituality and Chaplaincy in Palliative Care	Flannelly	2012-01-01	Journal Abbr Journal of Pain and Syr
The 'safe death': An ethnographic study exploring the p...	Rainsford et al.	2018	Management
The Role of Professional Chaplains on Pediatric Palliativ...	Cadge et al.	2011	Language English
The role of spirituality in palliative care	Rankin	2018	DOI 10.1016/j.jpainsymman.

Abstract
Addressing spiritual needs of seriously ill i

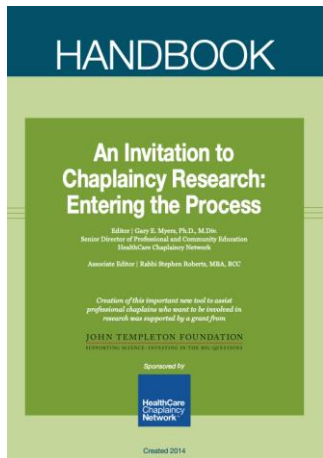


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We need all types of chaplain researchers! What's your type(s)?

These are overlapping, not mutually exclusive, non-hierarchical and not an exhaustive list.

- **Clinical:** Practitioner/research subject
- **Research Literacy:** Journal club, newsletters, webinars, digests summarizing research
 - ACPE, Duke, AAHPM, APC, Chaplaincy Innovations Lab, Transforming Chaplaincy
- **Advising:** Ethics and oversight – IRB, Ethics Committee, using basic knowledge about research to advocate for patients
- **Development:** Grant writing and donor cultivation to fund research
- **Quality Improvement:** Using evidence base to inform practice

What's your type(s)?

- Design and Writing
 - Qualitative
 - Case studies, letter to editors JPSM, JAMA, etc. , Op-Ed project
- Quantitative

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Critical questions for chaplaincy research in palliative care

- Supply vs. demand - “Self-Licking ice cream cone”
 - Sorting out what chaplains think is important to study and understand and balancing this with what we need to demonstrate to employers, funders, policy makers, etc.
- Assessment
- Effectiveness
- Spiritual distress
- Palliative Care Sub-specialites
 - Outpatient care
 - Pediatrics



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One chaplain's current involvement in research

- Pubmed alerts, developing a bibliography (for own practice, future writing, CPE curriculum)
- Attending conferences, seminars, webinars, etc.
- Spiritual Assessment
 - Spiritual AIM © Manual
 - Interrater reliability
 - Pre/post knowledge tests
- SpirPalOnc Database
 - Addition of "spiritual variables" to an extensive outpatient oncological palliative care database
 - Chart Review/Data Extraction - percentage of visits where chaplain screens and/or makes spiritual assessment
 - Feasibility of use of common documentation template, prevalence of certain spiritual needs, correlations between other palliative variables (i.e. anxiety, metastasis, hospice enrollment)

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Questions/Discussion

Thank you!

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